

Members

Sen. Marvin Riegsecker, Chairperson
Sen. Rose Ann Antich
Rep. Sheila Klinker
Rep. Robert Alderman
Sylvia Marie Brantley
Christopher Durcholz
Suda Hopkins
Sally Lowery
Ervin Picha
Joanne Rains
Thomas Van Meter
Betty Williams



INDIANA COMMISSION ON MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

LSA Staff:

Carrie S. Cloud, Attorney for the Commission
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MEETING MINUTES¹

Meeting Date:	September 2, 1999
Meeting Time:	1:30 P.M.
Meeting Place:	Auditorium, Community Mall Building, Fort Wayne State Developmental Center, 4900 St. Joe Road
Meeting City:	Fort Wayne, Indiana
Meeting Number:	3

Members Present: Sen. Marvin Riegsecker, Chairperson; Rep. Sheila Klinker; Rep. Robert Alderman; Sylvia Marie Brantley; Christopher Durcholz; Suda Hopkins; Ervin Picha; Joanne Rains; Thomas Van Meter; Betty Williams.

Members Absent: Sen. Rose Ann Antich; Sally Lowery.

LSA Staff Present: Carrie S. Cloud, Staff Attorney; Ron Sobecki, Fiscal Analyst.

Call to Order

Senator Riegsecker called the meeting to order at approximately 1:50 p.m., after Commission members had completed a brief tour of the center. After having the Commission members and staff introduce themselves, Senator Riegsecker thanked the

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persons in the audience for their attendance at the meeting and thanked the center's administration and staff for their cooperation in the tour.

Comments from the Family and Social Services Administration (FSSA) on the operation of Fort Wayne State Developmental Center (FWSDC)

Dr. Peter A. Sybinsky, Secretary of the Office of Family and Social Services, introduced himself to the Commission members. Dr. Sybinsky told the Commission that he has been on the job now for three and a half months, coming to Indiana after serving as the Director of the Health Department in Hawaii. Dr. Sybinsky reported that FSSA is undergoing many changes across the whole agency in order to achieve the agency's mission of helping people help themselves. Dr. Sybinsky explained that the agency is seeking to carry out its mission by developing actively responsible choices for all the individuals served by the agency. Dr. Sybinsky noted that these changes were taking place on many levels: workers in the field offices, organizational changes, and partnerships with business, labor, and advocacy groups.

In response to questions from Representative Alderman regarding the high turnover rate of persons in the top of FSSA's administration and the inconsistency that seems to accompany the turnover, Dr. Sybinsky declared that he is not someone who doesn't want the job for a long time and that he is committed to seeing that the agency spends all of the \$39 million dollars that was recently appropriated to reduce the waiting list for persons with developmental disabilities.

Representative Klinker requested that Dr. Sybinsky look into the possibility of utilizing the services offered by the vocational rehabilitation program in order to get job training for more residents of the center. Dr. Sybinsky stated that this was an area he would be willing to look into.

Senator Riegsecker commented that as the Commission has toured both state developmental centers this summer, he has heard many concerns from people who are afraid that the centers will be closed. Senator Riegsecker suggested that Indiana, and specifically FSSA, should develop a philosophy of doing what needs to be done for the residents and not just react to crises. Senator Riegsecker also stated that the developmental centers would be a fertile training ground for students from academic institutions in the state.

Representative Klinker suggested to Dr. Sybinsky that FSSA look into establishing facilities on the center's campus to deal with the special needs of those residents who are dually diagnosed individuals. Dr. Sybinsky told the Commission that he and Dr. Richard Feldman, Commissioner of the Indiana State Department of Health, have recently commissioned a group to develop a plan of how to get where the agencies want to be, and that the treatment of dually diagnosed individuals was a high priority.

In response to questions from Representative Alderman, Dr. Sybinsky stated that he would be very surprised if FWSDC was closed in the next five years. Dr. Sybinsky stated that the focus of the agency needs to be on providing the services needed by the population it serves, not on closing facilities. Dr. Sybinsky also stated that technological changes over the last few years have allowed many residents of state developmental centers who would have been expected to remain institutionalized for the remainder of their lives to move into community placements and that future advances in technology could continue that trend.

Senator Riegsecker remarked that there are many persons with developmental disabilities who have never been identified or had any contact with the system who would be needing

services in the future (e.g., when their care giver parents die or become too elderly to continue caring for them). Dr. Sybinsky noted that the agency owes these people the same attention as individuals currently in the system and that this is an issue that will be studied by the task force he and Dr. Feldman have created.

In response to questioning by Senator Riegsecker regarding a higher level of residents to staff persons at FWSDC than at Muscatatuck SDC, Dr. Sybinsky stated that each facility is different and has its own unique staffing needs based on many factors, including the type of residents served and the physical environment of the facility. Dr. Sybinsky remarked that the agency is currently developing objective staffing standards for each facility based upon the facility's unique needs.

Dr. Ajit Mukherjee, Superintendent of FWSDC, welcomed the Commission to Fort Wayne. Dr. Mukherjee acknowledged that in a facility the size of FWSDC, there are always going to be some problems and room for improvement, but that the facility is doing well. Dr. Mukherjee told the Commission that his philosophy for the center is that everything must be done to improve the quality of life of the residents. Dr. Mukherjee stated that the quality of care a person with developmental disabilities receives should not be different in an institution than in other settings (e.g., group home). Responding to the criticisms made by the United States Department of Justice (DOJ), Dr. Mukherjee observed that while the rules and regulations under which the center operates have not changed in many years, the interpretation of those rules has. For example, Dr. Mukherjee stated that FWSDC reported 1700-1800 injuries per month in 1991, as compared to 375 per month in 1998, but was only criticized by the DOJ in 1998. Dr. Mukherjee commented as follows to respond more specifically to the three main criticisms of the DOJ:

- (1) Community placement -- Since January of this year, 42 residents have been moved out of the center into community placements and approximately 75 residents are expected to have been placed in the community by year's end. The center's clinicians agreed with the DOJ regarding the 150 persons identified by the DOJ as being ready for community placement; it is just a matter of finding the placement and implementing the change.
- (2) Use of psychotropic drugs -- The use of psychotropic drugs at the center has been brought down some since the DOJ investigation. The center is trying to discontinue the use of older medications (e.g., those developed in the 1950's and 1960's), but for some patients these older medications work better than their newer counterparts.
- (3) Inappropriate use of restraints -- It is the desire of the center's administration to stop using any mechanical restraints by the end of this year and the center is currently working towards that end.

Dr. Mukherjee remarked that FWSDC was not in very bad shape and the DOJ did not assess any fines against the facility. Dr. Mukherjee stated his belief that the center could come into full compliance within 18 to 24 months.

In response to questioning by Representative Klinker, Dr. Mukherjee stated that he did not believe that the DOJ would criticize a facility for continuing to use some sort of physical restraints if there was a documented clinical need to do so in order to prevent a resident from causing injury to himself or others. Dr. Mukherjee expressed his belief that the removal of the restraint itself is not the key issue, but the focus should be on what replaced it.

Responding to questions from Senator Riegsecker, Dr. Mukherjee told the Commission that there are currently about 420 residents at the center and that all of them receive

Medicaid funding. The budget for the center this year is \$41 million, two-thirds of which is reimbursed by the federal government through Medicaid.

Public Testimony

John Dickerson, Executive Director of the ARC of Indiana, echoed the concerns of several Commission members regarding the fact that in the not-too-distant future there will be many more persons with developmental disabilities needing services due to a variety of factors, including the fact that medical advances are allowing persons with developmental disabilities to live longer and that many persons with developmental disabilities are being cared for by their parents who are also aging. Mr. Dickerson stated that while the waiting list for services is still significant, and may well grow as some of the previously unidentified persons come into the system, FSSA has been making substantial progress in implementing the 317 Task Force plan and reducing the waiting list.

Responding to questions from Representative Klinker, Mr. Dickerson stated that it would take approximately \$147 million (federal and state money combined) to end the current waiting list. However, Mr. Dickerson stated that the 317 Task Force plan envisioned ending the waiting list in stages and that an appropriation of \$40 to \$45 million in the next biennium would allow the reduction of the waiting list to continue according to that plan. Mr. Dickerson stated that these figures did not include any money for the revitalization or restructuring of institutional facilities to serve persons who would continue to reside in those settings.

Mr. Dickerson informed the Commission that FSSA has recently implemented a new budget tracking system that will allow the agency to follow the money appropriated by the General Assembly to assure that all the money is spent to provide the services needed. Mr. Dickerson remarked that he believed that it will be possible to accomplish more with the money than projected due to the efficiency allowed by this tracking system.

Representative Gloria Goeglein, whose legislative district encompasses FWSDC, thanked the Commission for meeting at the center. Representative Goeglein noted that when the Commission members took their tour of the center before the meeting, they were not shown the most severely disabled residents or told about the many overtime hours that staff must work. Representative Goeglein also commented to the Commission that many of the problems faced by the developmental centers are faced by group homes as well, particularly the lack of workers, and that this is an issue the Commission might want to study. Representative Goeglein also expressed concern with the amount of money being paid to consultants at the developmental centers which could possibly be used to hire more full-time staff.

Linda Martan, the cousin of a resident at FWSDC, expressed her belief that the Commission members were not always receiving the full picture of the conditions at FWSDC. She told the Commission members that her cousin had been the victim of abuse and theft while residing at FWSDC and that she and other family members had not been successful in getting these problems addressed. The Commission expressed its concern that these types of incidents may be occurring at the center and directed Ms. Martan to speak to Dr. Mukherjee and Dr. Sybinsky.

Gary Jackson, who cares for his 52-year-old developmentally disabled brother in his home, expressed his frustration that the system does not have a single "clearinghouse"-type agency that can help guide families through the complicated system. Mr. Jackson also expressed his frustration over the fact that the law does not allow his brother to be placed into a nursing home, even for the short term. Representative Klinker stated that perhaps

the requirement of pre-screening for entrance into a nursing home is something that should be looked into again to determine if it would create additional, viable options for caring for persons with developmental disabilities.

Sheri Caveda, mother of three children with developmental disabilities and Chairperson of the Long-Term Care Committee for the Council of Volunteers and Organizations for Hoosiers with Disabilities (COVOH), remarked that the current system trying to serve persons with developmental disabilities is archaic. Ms. Caveda stated that many community supports are so stressed that they are almost nonexistent. Ms. Caveda declared that the workers do not exist to care for the persons who will be moved out of institutions into the community. This lack of workers, she explained, is due to many reasons, including low pay scale, lack of benefits, poor or no training, transportation problems, and child care issues. Ms. Caveda urged the Commission to investigate new alternatives and commit new financing to address long-term care issues as the system will continue to have more demands placed upon it due to the growing elderly population and more developmentally disabled persons being identified. In response to a question from Representative Klinker regarding Ms. Caveda's children, Ms. Caveda stated that it would be much easier if she were able to hire care givers herself than to have to go through an agency.

John Guingrich, Program Director of the League for the Blind and Disabled, asked the Commission members to keep in mind that it is important to determine who decides what the quality of life should be for persons with disabilities -- the individuals and their families, or people in the system. Mr. Guingrich asserted that individuals with developmental disabilities need to be stimulated to achieve new levels of achievement, not just treated to remain where they are. Mr. Guingrich echoed earlier witnesses' testimony about how difficult it is to navigate the system, even for social service organizations. Mr. Guingrich also stated that some of the reasons that it is difficult to find or retain community care workers include no training, low pay, and lack of advancement.

Carolyn Matczack, parent of a daughter at FWSDC, told the Commission that many professionals do not want to work with developmentally disabled persons and that education of those professionals regarding the needs of persons with developmental disabilities was perhaps needed. Ms. Matczack also stated that while many families do take on the responsibility of caring for a developmentally disabled relative at home, every family can not be expected to do so.

Mary Harmon, mother of a daughter who has resided at FWSDC for 41 years, told the Commission that she has never had a bad experience with the staff or the quality of care that her daughter has received.

Fredus Peters, father of a son who has resided at FWSDC for 23 years, told the Commission that he has never had a problem with the care his son receives at FWSDC. Mr. Peters also stated that the facility has a Human Rights Committee that is responsible for looking into allegations of abuse or other misconduct such as the allegations reported by a previous witness. In addition, Mr. Peters expressed concern over some information he had received indicating that a certain portion of the \$39 million recently appropriated to reduce the waiting list for services would have to be reverted to the general fund and therefore could not be spent to provide needed services. Commission members assured Mr. Peters that they would be watching that issue very closely and would do everything they could to see that all the money was spent.

Steve Hinkle, staff member of the ARC of Northeastern Indiana, expressed his appreciation to the Commission for coming to FWSDC but asked the Commission to try to

find ways to improve the system so that the next time the Commission comes to FWSDC, it can be for a good reason. Mr. Hinkle stated that the system needs more staff and better training for staff at both the institutional and community levels.

Don Borem, parent of a daughter who has lived at FWSDC for 21 years, informed the Commission that he has never had a problem with the center or the care his daughter receives there. Mr. Borem also stated that in all the years she has lived at FWSDC, his daughter has never once hesitated to return to the center after a visit home.

Adjournment & Next Meeting

There being no further business to come before the Commission, Senator Riegsecker adjourned the meeting at approximately 3:40 p.m.

The next meeting of the Commission will be held on Monday, September 13, 1999, at 10:30 a.m. in Room 233 of the State House. (Indications of meeting dates and times in these minutes are subject to change. Please refer to the most recent Calendar of Meetings distributed by the Legislative Information Center for official meeting information.)